

The House Committee on Rules offers the following substitute to HR 590:

## A RESOLUTION

1 Creating the House Study Committee on Pediatric Acute-Onset Neuropsychiatric Syndrome  
2 ("PANS") and Pediatric Autoimmune Neuropsychiatric Disorder Associated with  
3 Streptococcal infection ("PANDAS"); and for other purposes.

4 WHEREAS, PANS and PANDAS create the sudden onset of obsessive-compulsive disorder  
5 in children, causing previously healthy and emotionally adjusted children to experience  
6 severe anxiety and emotional disturbances; and

7 WHEREAS, children with PANS and PANDAS tend to manifest some of the following  
8 symptoms: tics or other abnormal movements, severe separation anxiety, generalized anxiety,  
9 irritability, aggression, personality changes, Attention Deficit Hyperactivity Disorder,  
10 marked deterioration in learning and school performance, and developmental regression,  
11 including regression in handwriting; and

12 WHEREAS, the National Institutes of Mental Health ("NIMH") estimates that 1 in 200  
13 children have PANS or PANDAS, meaning these diseases affect roughly 20,000 children in  
14 Georgia; and

15 WHEREAS, PANS and PANDAS affect a small subpopulation of patients but have a  
16 disproportionately high economic, clinical, and social burden for patients, their caregivers,  
17 families, employers, and the health care system; and

18 WHEREAS, children with PANS and PANDAS may experience moderate to dramatic  
19 improvement with antibiotics, intravenous immunoglobulin treatment, or plasmapheresis;  
20 and

21 WHEREAS, the NIMH suggest that with appropriate early diagnosis and intervention  
22 therapies, up to 25-30 percent of childhood mental illnesses may be preventable and may  
23 prevent further long-term decline and potentially permanent disability; and

24 WHEREAS, identifying the barriers to PANS and PANDAS—awareness, testing, diagnosis,  
25 and early linkage to medication and care—would be in the state's best interest; and

26 WHEREAS, many general pediatricians, nurse practitioners, and pediatric subspecialists are  
27 not familiar with the most current diagnostic criteria and treatment guidelines for these  
28 disorders; and

29 WHEREAS, in addition to lack of access to treating providers, many insurers do not cover  
30 treatment for PANS and PANDAS, which can cost many tens of thousands of dollars,  
31 placing it out of reach for most families; and

32 WHEREAS, researchers at the NIMH are currently engaged in extensive research and testing  
33 on how to effectively treat PANS and PANDAS; and

34 WHEREAS, researchers at Moleculera Labs at the University of Oklahoma have developed  
35 PANS and PANDAS blood testing procedures; and

36 WHEREAS, the University of Arizona and Banner Health System in Arizona have opened  
37 the first Centers for Post-Infectious Autoimmune Encephalopathy, providing insurance-based  
38 access to expert care and consultative services for general and subspecialist pediatricians  
39 around the country; and

40 WHEREAS, the deep medical and bioscience resources in Georgia make our state well  
41 situated to meaningfully contribute to best medical practices, research, and medical  
42 technology to advance the early diagnosis and treatment of children with PANS and  
43 PANDAS; and

44 WHEREAS, the Southeastern PANS/PANDAS Association is a Georgia-based nonprofit  
45 organization dedicated to expanding access to expert, insurance-based care for children and  
46 families suffering from PANS and PANDAS in our region; and

47 WHEREAS, it is in the state's best interest that there be greater public awareness of this  
48 serious health issue among parents, medical providers, and policy makers in Georgia; and

49 WHEREAS, it is imperative to undertake a study of the needs, issues, and problems  
50 associated with this disorder; and

WHEREAS, it would be beneficial to:

- (1) Study the benefit of improved awareness and early diagnosis of PANS and PANDAS among medical providers;
- (2) Examine comprehensive medical and behavioral health services for those suffering from this serious autoimmune disorder which have been demonstrated to have a positive impact on medical outcomes and reduced burdens on patients, families, providers, and society; and
- (3) Identify barriers to insurance-based care for children with PANS and PANDAS and their families.

NOW, THEREFORE, BE IT RESOLVED BY THE HOUSE OF REPRESENTATIVES:

- (1) **Creation of House study committee.** There is created the House Study Committee on PANS and PANDAS.
- (2) **Members and officers.** The committee shall be composed of five members of the House of Representatives to be appointed by the Speaker of the House of Representatives. The Speaker shall also appoint an additional three nonlegislative members of the committee as follows: one practicing psychiatrist, one practicing pediatrician, and one public health practitioner. The Speaker shall designate a legislative member of the committee as chairperson of the committee.
- (3) **Powers and duties.** The committee shall undertake a study of the conditions, needs, issues, and problems mentioned above or related thereto and recommend any action or legislation which the committee deems necessary or appropriate.
- (4) **Meetings.** The chairperson shall call all meetings of the committee. The committee may conduct such meetings at such places and at such times as it may deem necessary or convenient to enable it to exercise fully and effectively its powers, perform its duties, and accomplish the objectives and purposes of this resolution.
- (5) **Allowances, expenses, and funding.**
  - (A) The legislative members of the committee shall receive the allowances provided for in Code Section 28-1-8 of the Official Code of Georgia Annotated.
  - (B) Members of the committee who are state officials, other than legislative members, or who are state employees shall receive no compensation for their services on the committee, but they may be reimbursed for expenses incurred by them in the performance of their duties as members of the committee in the same manner as they are reimbursed for expenses in their capacities as state officials or employees.
  - (C) Members of the committee who are not legislators, state officials, or state employees shall receive a daily expense allowance in an amount the same as that specified in subsection (b) of Code Section 45-7-21 of the Official Code of Georgia

87 Annotated, as well as the mileage or transportation allowance authorized for state  
88 employees.

89 (D) The allowances authorized by this resolution shall not be received by any member  
90 of the committee for more than five days unless additional days are authorized. Funds  
91 necessary to carry out the provisions of this resolution shall come from funds  
92 appropriated to the House of Representatives; except that funds for the reimbursement  
93 of the expenses of state officials, other than legislative members, and for the  
94 reimbursement of the expenses of state employees shall come from funds appropriated  
95 to or otherwise available to their respective agencies.

96 **(6) Report.**

97 (A) In the event the committee adopts any specific findings or recommendations that  
98 include suggestions for proposed legislation, the chairperson shall file a report of the  
99 same prior to the date of abolishment specified in this resolution, subject to  
100 subparagraph (C) of this paragraph.

101 (B) In the event the committee adopts a report that does not include suggestions for  
102 proposed legislation, the chairperson shall file the report, subject to subparagraph (C)  
103 of this paragraph.

104 (C) No report shall be filed unless the same has been approved prior to the date of  
105 abolishment specified in this resolution by majority vote of a quorum of the committee.  
106 A report so approved shall be signed by the chairperson of the committee and filed with  
107 the Clerk of the House of Representatives.

108 (D) In the absence of an approved report, the chairperson may file with the Clerk of the  
109 House of Representatives a copy of the minutes of the meetings of the committee in lieu  
110 thereof.

111 **(7) Abolishment.** The committee shall stand abolished on December 1, 2019.